

House Energy and Commerce subcommittee on Health
June 25, 2015 Hearing on Public Health legislation: H.R. 2820, H.R. 1344, and H.R. 1462
Congressman David W. Jolly statement for the record

Mr. Chairman, I want to thank you and the members of the committee for expediting this hearing on H.R. 2820, the Stem Cell Therapeutic and Research Act of 2015, legislation of which I am a proud original cosponsor.

As you know, this is the legislation that authorizes the miraculous, life-saving work of the C.W. Bill Young Cell Transplantation Program, which this committee in a previous authorization bill named for my predecessor. It holds a special place in my heart and the heart of so many people in the 13th Congressional District of Florida I represent. It was there almost 30 years ago that this program had its birth when a young 11-year-old girl named Brandy Bly befriended Bill and Beverly Young. Brandy was a patient at All Children's Hospital where she was admitted with a form of leukemia for which the only treatment was a bone marrow transplant. The only problem was that Brandy had no siblings and thus no chance for finding a matched donor. You see, there was no National Marrow Donor Program at the time.

Brandy died from leukemia before she could turn 12 and it was in the hallway the night she died that Bill Young asked her doctors what could have been done to save her life. The answer was a bone marrow transplant from an unrelated donor. By some divine providence, All Children's Hospital was home to the research work being done by Dr. Bob Good, the doctor credited with pioneering the procedure known as unrelated marrow transplantation. He proved that the success rate of bone marrow transplants between perfectly matched family members could be virtually the same as those between perfectly matched complete strangers.

The challenge was being able to match perfect strangers, because on average, the chance of any two unrelated individuals being perfect matches is one in 20,000. Thus began the work of Bill Young, to learn everything he could about the science of bone marrow transplantation and the mechanics of establishing a national registry to match volunteer donors with terminally ill patients whose only hope was a bone marrow transplant.

Many doors were slammed in his face along the way and the National Institutes of Health, in a hearing of this very subcommittee, even told him early on that a national registry would never work and he would never recruit more than 50,000 potential donors.

Along the way, Bill Young's path eventually crossed that of Admiral Elmo Zumwalt, the legendary former Chief of U.S. Naval Operations, whose own son died of leukemia because he could not find a matched donor. Together they joined forces along with a few other early pioneers to establish a national registry. Their search led them to the United States Navy, which had an interest in marrow transplantation, and with an infusion of \$1,500,000 by Congressman Young into a Navy medical research account in 1986, the national registry was born.

It was on December 16, 1987, Bill Young's birthday, that the National Marrow Donor Program matched its first donor and patient, harvested its first bone marrow donation, and shipped it from Milwaukee in a driving snowstorm to a waiting patient in North Carolina.

From there the program has grown and flourished. Bill Young would travel the country to promote the national registry, picking up families of searching patients along the way. He even recruited his colleagues and staff in the House and Senate. The registry grew slowly to 100,000 potential donors then to 250,000. Congressman Young had the idea in 1990 to fund a special program at the Department of Defense to recruit service members, the ultimate volunteers, to join the national registry. He knew from the Navy that bone marrow transplantation was the preferred method of treatment of our troops who might be exposed to a chemical weapons attack during Operation Desert Storm.

Today, I am proud to report, that the national registry has more than 12,500,000 potential donors in our national registry and with its linkage to national registries across the world, searching patients have access to more than 24,500,000 potential donors.

Bone marrow and cord blood transplantation is a preferred method of treatment for many forms of leukemia and blood cancers with the number of diseases totaling more than 70. In addition, as Bill Young predicted many years ago, bone marrow transplantation would be a cure for many other diseases, including today sickle cell anemia. Since 1987, more than 68,000 patients have received the living gift of life from a donor on the national registry. Last year alone, 6,300 patients received a transplant. These are children, mothers and fathers, brothers and sisters all of whom are alive today or at least received a few extra years of life from the gift of bone marrow or a cord blood transplant from a complete stranger.

Mr. Chairman, our colleagues in the House and Senate, past and present, can take great pride in what we have done together to establish this program, to fund this program, to authorize this program, and to grow and support this program that has saved enough lives to fill one of our nation's largest stadiums.

We are here today, though, because our work is not done. We need to authorize the work of the National Marrow Donor Program for another five years to continue saving lives and to continue to give hope for patients searching for that matched stranger that will give them that chance at life. You see, we still need to recruit more donors, especially among minority populations, because genetically, patients will most likely find a matched donor from a similar ethnic background. Donor recruiters all around the country are working hard to increase minority participation, as close to half of all new donors are minorities. As Bill Young used to say though, our job is not done until every one of the searching patients can find a donor. For the 14,000 patients who need an unrelated transplant annually, that is their only hope for a cure.

Your colleague Doris Matsui and I are proud co-chairmen of the bipartisan Congressional Caucus to Cure Blood Cancers and Other Blood Disorders. The members of our caucus look

forward to working with you and the members of your committee to carry on the legacy of Bill Young and the work he began 30 years ago this year to establish, fund, and support the National Marrow Donor Program and its dedicated network of transplant centers, donors centers, donor recruitments organizations, and individuals who simply want to save a life.

Mr. Chairman, thank you for your time today, your longtime support of this program, and your commitment to move this authorization legislation through this Congress as soon as possible. I can think of no more important legislative effort to our colleagues as it is a program that touches virtually every district across our nation.